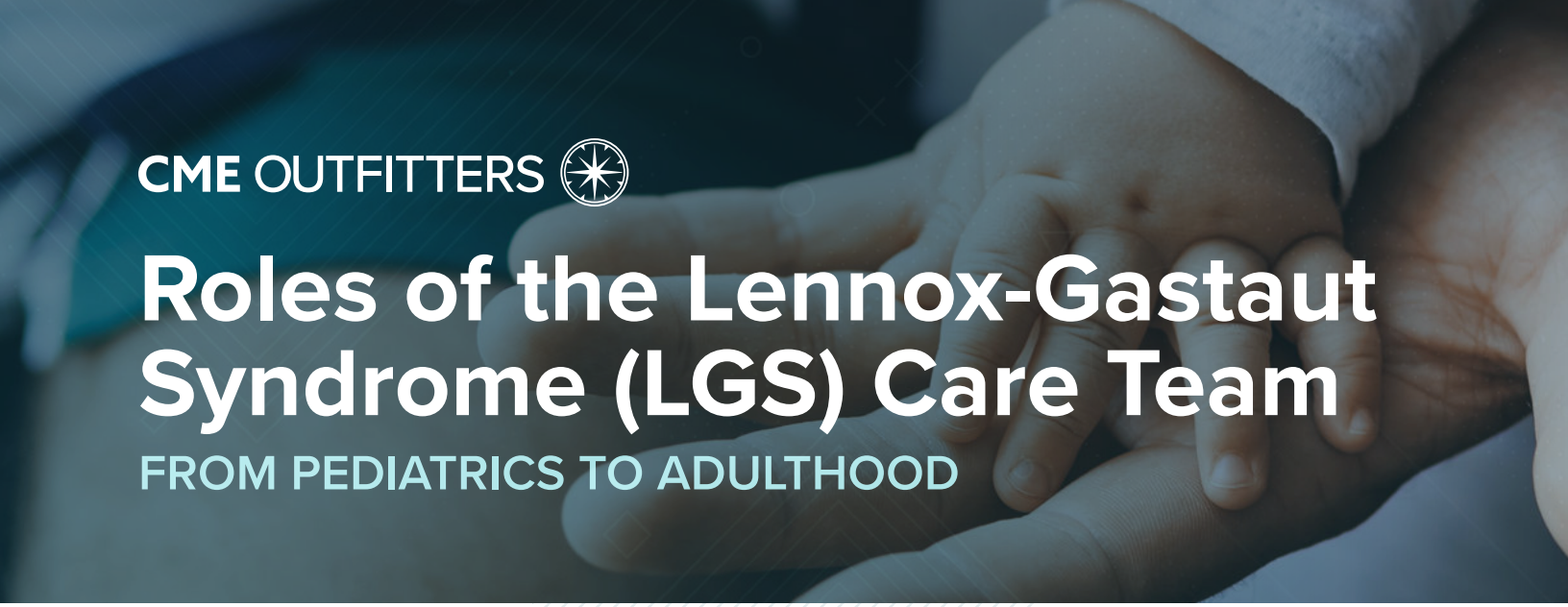

CME OUTFITTERS

Roles of the Lennox-Gastaut Syndrome (LGS) Care Team

FROM PEDIATRICS TO ADULTHOOD

This resource outlines the interdisciplinary team members involved in caring for individuals living with LGS from childhood through adulthood. It is designed to help clinicians, caregivers, educators, and residential team members understand each team member's role, improve communication across all settings, and support long-term planning. Use this guide to clarify responsibilities, coordinate services, and ensure continuity of care during key transitions, including the shift from pediatric to adult care.

> This resource uses person-centered language to emphasize the abilities, preferences, and support needs of individuals living with LGS across all stages of care.

Pediatric Phase (Childhood and Adolescence)

Pediatric Neurologist/Pediatric Epileptologist

- Confirms LGS diagnosis (seizure types and the characteristic electroencephalogram [EEG] slow spike-and-wave pattern)
- Manages anti-seizure medications (ASMs), rescue therapies, and dietary therapies
- Coordinates referrals to developmental, behavioral, and therapy services
- Initiates early discussion of long-term planning and evaluates candidacy for newer antiseizure treatments or device-based interventions when appropriate

Epilepsy Neurosurgeon/Epilepsy Surgery Team

- Evaluates individuals with uncontrolled seizures for surgical or device-based interventions (such as vagus nerve stimulation or corpus callosotomy)
- Works with neurology to determine candidacy based on seizure type, frequency, safety, and treatment history
- Preoperative counseling and postoperative follow-up to ensure coordinated long-term care

Pediatric Epilepsy Nurse/Nurse Practitioner

- Provides seizure education and first-aid training
- Teaches families how to use rescue medications
- Supports families and overall care coordination across home, school, and community settings
- Reinforces medication adherence and safety planning

Developmental Pediatrician

- Assesses cognitive, communication, and social development
- Recommends early intervention or school-based supports to address developmental needs
- Assists in identifying developmental regression or plateauing

Primary Care Pediatrician

- Oversees routine health maintenance, vaccinations, and common childhood illnesses
- Manages referrals to subspecialists
- Coordinates with neurology and family/caregivers to ensure whole-child care across all domains

Therapists

- **Physical Therapist:** Motor issues, gait instability/fall prevention, mobility aids
- **Occupational Therapist:** Dressing, feeding, fine motor skills, equipment needs
- **Speech-Language Pathologist:** Supports communication using speech, language, and augmentative/alternative communication (AAC) approaches; evaluates feeding and swallowing safety

Dietitian/Nutrition Specialist

- Guides the use of ketogenic or modified dietary therapies when appropriate
- Monitors growth, nutritional status, and metabolic labs during dietary therapy
- Coordinates with the neurologist to adjust dietary plans based on seizure response and side effects

Genetic Counselor

- Supports evaluation for potential genetic or metabolic causes of LGS
- Educates families regarding testing options, results, recurrence risks, and implications for care planning
- Coordinates genetic testing recommended by the neurology team

These services are critical due to the high prevalence of motor, mobility, and communication challenges in LGS.

Medical Subspecialists

- Includes cardiology, pulmonology, gastroenterology, orthopedic, and endocrinology as needed
- Evaluate and manage cardiopulmonary, gastrointestinal (GI), musculoskeletal, and endocrine conditions that impact daily life
- Coordinate with adult neurology, primary care, and residential teams to ensure comprehensive treatment
- Address issues such as sleep-disordered breathing, aspiration risk, and chronic GI needs
- Assist with mobility concerns, bone health, and medication-related side effects
- Coordinate with neurology and primary care to ensure whole-person care

School/Educational Team

- Develops and updates the Individualized Education Program (IEP)
- Provides seizure action plans in the school setting
- Creates behavioral and safety supports, including precautions for atonic (drop) seizures
- Coordinates therapies delivered at school

Behavioral Health (Psychology/Psychiatry)

- Addresses anxiety, behavioral challenges, and sleep disturbances
- Provides coping strategies for caregivers and staff

Caregivers/Guardians

- Primary decision-makers in early years
- Monitor seizures, behaviors, sleep, and quality of life
- Serve as the patient's primary advocates in all settings

As children with LGS enter adolescence, care must gradually shift toward fostering independence, preparing for adult systems of care, and ensuring continuity across medical, educational, and social services.

Transition Phase (Approx. 14-22 years)

Transition requires preparing individuals with LGS, families, and systems for adult care. Many individuals with LGS need structured support for cognitive and communication challenges. Begin transition planning early – ideally starting between ages 12-14 – with check-ins each year to build skills, update goals, and prepare for transfer to adult care. This phase focuses on preparing the individual and caregivers for adult systems.

Transition Coordinator/Social Worker

- Plans the transfer to adult neurology
- Identifies needed adult services (day programs, vocational supports, residential options)
- Guides families through insurance, guardianship, and supported decision-making
- Connects families to community resources (state disability offices, respite services) while honoring the individual's preferences and communication style

Neuropsychologist/Psychologist

- Conducts evaluations for adult service eligibility
- Recommends appropriate supports to match the individual's needs
- Assesses decision-making capacity
- Guides communication approaches to support patient involvement

Palliative Care Team/Consultative

- Supports symptom management, comfort strategies, and coordination of care in all settings
- Guides families in defining goals of care and navigating challenging decisions while keeping the individual's preferences and well-being central
- Offers emotional and practical support for families; involvement does not indicate end-of-life care

Advocacy Organizations

- Provide transition checklists, long-term care resources, and peer support
- Offer contact information for peer support networks

Pediatric & Adult Teams/Joint Role

- Share medical records, seizure history, and behavioral care plans
- Monitor imaging and EEG results
- Provide information on applicable medication trials
- Create a concise transition summary outlining:
  - Seizure types and severity
  - Effective/ineffective medications
  - Rescue plan
  - Communication strategies
  - Behavioral considerations
  - Equipment needs

Key Transition Milestones

- Ages 12-14: Introduce transition concepts; identify communication and decision-making supports
- Ages 14-18: Build self-advocacy skills at the patient's level; update medical summary annually; explore guardianship or alternatives such as supported decision-making depending on the individual's needs
- Ages 18-22: Complete transfer to adult neurology; connect with adult services, housing, day programs; ensure caregiver supports remain in place

As the individual approaches adulthood, responsibilities transition fully to adult neurology, primary care, community programs, and residential supports, requiring coordinated handoffs and clear communication across teams.

Adult Phase (Adulthood → Long-Term Care)

Adult Epileptologist/Neurologist

- Oversees seizure and non-seizure symptom management
- Manages medications and rescue therapies; evaluates candidacy for device-based or surgical interventions when appropriate
- Coordinates with group homes, caregivers, and primary care
- Manages comorbidities emerging with age (e.g., osteoporosis, cardiac risk, mobility decline)

Adult Primary Care Provider/PCP

- Manages routine screenings and chronic illnesses
- Offers vaccinations and other preventive care measures
- Addresses non-neurologic issues (GI, endocrine, sleep, bone health)
- Ensures continuity across specialists

Residential Staff/Direct Support Professionals

- Provide daily support, including safety monitoring, communication assistance, and medication administration in residential settings
- Monitor for repetitive seizures without full recovery, behavioral changes, and sleep disturbances
- Assist with mobility, hygiene, and nutrition
- Communicate changes promptly to caregivers and clinicians

Adult Behavioral Health (Psychology/Psychiatry)

- Addresses behavioral challenges, anxiety, and sleep issues that affect daily life
- Evaluates psychotropic medication needs
- Supports caregivers managing chronic stress and trauma

Medical Subspecialists

- Evaluate and manage cardiopulmonary and GI conditions
- Provide orthopedic care and access to endocrinology
- Coordinate with adult neurology, primary care, and residential teams to ensure comprehensive treatment

Adult Therapists

- **Physical Therapist:** Supports mobility, balance, strength, and safe participation in activities of daily living (ADLs), including transfers and fall prevention; works with the team to ensure the person can physically access communication devices and environments
- **Occupational Therapist:** Provides adaptive equipment and teaches functional living skills
- **Speech-Language Pathologist:** Offers communication devices, monitors swallow safety, and guides feeding strategies

Case Manager/Service Coordinator (State or Agency)

- Secures day programs, transportation, and housing supports
- Coordinates benefits, insurance renewals, and community support
- Assists with long-term planning (e.g., guardianship, financial supports, employment services)

Caregivers/Guardians

- Continue to advocate for quality of life and care consistency
- Participate in treatment decisions and supported decision-making
- Ensure communication across medical, behavioral, and residential teams

How Roles Change Over Time

Pediatric focus: developmental support, school-based services, and family-centered care

Pediatrics → Transition

- Pediatric teams provide developmental, educational, and family support.
- Transition period includes planning for adult systems, legal considerations, and autonomy-supportive decision-making.
- Communication needs and safety risks must be reassessed.

Adult focus: safety in community and residential settings, chronic disease management, and long-term quality of life

Transition → Adulthood

- Adult care prioritizes safety, stability, and non-seizure symptom management across medical and community systems.
- Residential programs and adult support staff often take on daily care roles previously handled by family.
- Adult systems require new documentation, reevaluation, and formal coordination.

Across All Phases

- Caregiver burden remains high; continuous support is essential.
- Shared and supported decision-making must remain central.
- Seizure action plans and supported decision-making tools should evolve to match living environments, so all team members understand their responsibilities.
- Collaboration is required at every stage.
- Additional specialists can be included based on the individual's treatment plan and changing clinical needs.
- As needs arise, subspecialists can be included to address medical comorbidities and support long-term care.
- Palliative care specialists may be involved at any stage to support symptom management, care coordination, and family well-being.
- Promote safety, communication support, and continuity of care in all settings.
- Adding a Clinical Pharmacist (hospital or outpatient, as available) to the team is optional.
  - Reviews ASM regimens and potential drug-drug interactions
  - Supports safe titration, side effect monitoring, and adherence strategies
  - Educates caregivers and residential staff about medication timing, administration, and what to watch for
- All members of the team share responsibility for supporting communication, honoring preferences, promoting safety, and ensuring the individual's needs are met.